

Dear Jack and committee members,

Thank you for the continued recognition and careful considerations of the struggles of those navigating metastatic breast cancer (MBC) in Wales. However, we feel the need to respond once more to demand follow-up and accountability from a few of the statements made in the health ministers' response to yourselves.

I am pleased to see some much-needed steps are being considered, such as work towards finally receiving a recognised MBC pathway from the Wales Cancer Network. The health minister has stated a timeframe cannot be given until completion, but as MBC patients continue to suffer in silence, I must insist on enquiring how the progress will be measured and who will be accountable for ensuring this does get completed? Will patients also be involved in the pathways design?

It is indeed another positive step to have had the deferred recommendations for MBC patients presented to the Network Board in January. As well as a confirmation of a recommendation working towards an MBC pathway. Yet what are the other key outcomes of this meeting and paper? And where and when will this information be made available? It will be crucial to maintain transparency during these key stages to ensure all persons interested can continue to work towards building better care for those with MBC.

The new £11 million data investment to help replace the functionality of the Cancer Network Information System Cymru (CaNISC) is also hugely welcomed. Although if the investment is set up for the development and running of the new system and not for "interrogating its data outputs", then how will it tackle our need for collection of data of those living with MBC? How will the patients see any benefit or data when it is not clear how the new system will 'count' patients to begin with?

I am very happy to be aware of the 'C the signs' pilot portal for GP's. One of the key setbacks we are facing when it comes to diagnosing advanced breast cancer is being able to directly link the red flag symptoms of MBC from a patient which has already suffered primary BC. Can the minister ensure and confirm that the signs and symptoms of MBC will be included within the Health Boards treatment summaries in Wales? By empowering patients with better re-occurrence knowledge during the end of treatment summaries we can help lessen the risk of these life-threatening symptoms being overlooked.

Finally, I would like to address the final point regarding the health minister's expectations of MBC patients to be supported by cancer nurse specialists. As well as evidence stated previously by way of the named petition and additionally signed open letter to show the need for support for MBC Welsh patients, we now have access to the results of the Wales Cancer patient experience survey which shows us the short comings of holistic needs being addressed across all cancers. More than a third of people (36%) said they were not offered information about how to access financial help or benefits. Every person treated for cancer in Wales should be offered access to this information due to the financial impact a cancer diagnosis can have. More unfortunately, larger than two thirds (70%) said they had not been offered a written care plan, which should be routinely offered to every person with cancer in Wales. These figures hide the specifically challenging issues facing MBC patients from the NHS in Wales, because they do not even have a dedicated key worker to support or refer them to third sector resources.

Thank you for considering all points brought forward from my response and I hope the petitions committee will be able to continue to help us move forward with this crucial work.

Yours sincerely, Tassia Haines

